

MEDICAL CARE TASK FORCE REPORT

HEALTH ISSUES FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

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State of Washington



Department of Social and Health Services
Division of Developmental Disabilities

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Linda Rolfe, Acting Director of Developmental Disabilities, is to be commended for recognizing that consistent, quality health care is seriously compromised for individuals with developmental disabilities who live in the community. Contributing causes are unreliable or non-existent medical records and lack of education for health care providers. The Health Care Task Force members would like to thank Linda Rolfe for supporting this work to identify barriers and make recommendations for improving health care for individuals with developmental disabilities.

The members would also like to thank the people who so willingly contributed their time and expertise to assist this task force with their presentations at our meetings and/or who shared their experiences and expertise by phone or written reports. A list of contributors can be found in **METHODS**.

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I. INTRODUCTION

Purpose

The Division of Developmental Disabilities (DDD) has long been concerned about the inadequate individual health monitoring via the exchange of an individual's health records. The Division recognized that health care information about health conditions (medications, syndromes, etc.) that affect individuals with developmental disabilities is not always readily or easily accessible to health care providers.

The Health Care Task Force was given the charge to examine health-monitoring options for individuals with developmental disabilities and recommend system changes that will improve those individuals' ability to ensure that their health records are readily accessible to health care providers.

Further, the Task Force was asked to explore how we might harness our specialized knowledge and make it more readily and easily accessible to community health professionals.

Expected Outcomes

Recommendations on system changes that will improve individuals' ability to ensure that their health records are readily accessible to health care providers and

Recommendations on ways to harness our specialized knowledge, and make it more readily and easily accessible to community health professionals.

...To examine health-monitoring options for individuals with developmental disabilities and recommend system changes:

Health records ... readily and easily accessible

Specialized knowledge accessible to health professionals

... an infrastructure for health care management...

Person centered health care delivery

Population based health care delivery

II. EXECUTIVE SUMMARY

In February of 2001, Acting Director of the Division Developmental Disabilities, Linda Rolfe, convened a workgroup to develop recommendations on how to improve access to health care records for individuals with developmental disabilities by health care providers and to identify ways to share the expertise and resources the Division of Developmental Disabilities (DDD) currently possesses with community health care providers.

Based on the information collected, the task force concluded that medical care provided to individuals with developmental disabilities is fragmented, isolated, and not easily accessible. Racial, ethnic, and cultural disparities exist. There is paucity of medical knowledge of issues that are unique to developmental disabilities. Therefore, a goal of the task force is for the Division of Developmental Disabilities to implement changes that will achieve comprehensive, culturally competent, individualized, and community based health care services for individuals with developmental disabilities. Additionally, there needs to be emphasis on prevention and wellness.

Recommendations for Systems Infrastructure

The task force urges the health care community, at large, to develop an infrastructure for health care management for individuals with developmental disabilities. Recognizing that other partners are critical to success, the Division of Developmental Disabilities needs to coordinate with the Medical Assistance Administration, Mental Health Division, Department of Health, advocacy groups, family support organizations and community providers for health care services. Other agencies may be highly involved, however, the Division of Developmental Disabilities must lead the effort to create an infrastructure that will enable the coordination of existing systems and develop internal systems unique to individuals with developmental disabilities. The following recommendations are listed in order of priority and are not mutually exclusive.

1. PERSON CENTERED HEALTH CARE DELIVERY

A. The Secretary of DSHS should take the responsibility for assuring that Medical Homes are available for everyone with a developmental disability to provide and coordinate medical care. There is currently a Medical Home Leadership Project in place for children coordinated through the University of Washington, Center for Human Development and Disability.

B. The Division of Developmental Disabilities should provide Health Coordinators as an essential component for **person centered health planning**. Their function is coordinating primary care including wellness and preventive care, person centered health planning, specialty medical care, therapies and adaptive equipment, emergency care, hospitalization and education/training. Health coordinators are an essential function of Medical Homes but could stand alone if a Medical Home did not exist.

2. POPULATION BASED HEALTH CARE DELIVERY

A. The Division of Developmental Disabilities should establish a Centralized Statewide Support System to be in place to coordinate Regional Medical Resource Centers or serve as the sole resource at the state level. DDD responsibilities are:

- To partner with the Developmental Disabilities Council, to advocate for expanded curriculum development, and coordination for training of physicians and allied health professionals currently in practice and/or training.
- To provide a toll free number to assist physicians with complex DD issues.
- To develop and maintain a web site as a resource for specialized information.
- To implement guidelines for and provide technical assistance for health care providers, individuals, families, and care givers in maintaining medical information.
- To designate or identify Regional Medical Resource Centers in providing medical care management

B. DDD should identify Regional Medical Resource Centers, based on geography, to assist individuals with developmental disabilities in managing their medical care. The Centers' responsibilities would be to provide:

- Referral assistance for primary and specialty care.
- Assistance to the individuals and health care providers in the management of medical records and other necessary medical information.
- Coordination for training programs between the University of Washington and other educational facilities for primary care physicians, nurses, hospitals etc.
- Coordination with the University of Washington and other academic centers for training of residents and students (medical and allied health);
- Technical support to local health practitioners.
- Outreach to remote areas by arranging consultations with traveling teams.
- Continued use of Residential Habilitation Center (RHC) clinical staff expertise to provide education and support for community health care providers.
- health care at an RHC for an individual unable to locate a community health care provider until a community health care provider can be identified.

Recommendations for Medical Records

A. Standardized Medical Records

DDD should lead the effort to incorporate the expertise of medical providers in establishing guidance for basic essential components to be included in any medical records information system:

- a. A set of **standardized medical and health elements** to record all medical information.
- b. A **wallet size card** or a **medical alert bracelet** summarizing essential medical information including allergies, presence of prostheses, etc.

B. Health Records Systems

DDD must decide which of the following three ways are most appropriate to ensure that health information is readily and easily accessible to health care practitioners.

- a. **Web based Medical Records:** The standard medical chart and information to be kept on the World Wide Web. DDD could build their own system or contract with one of the commercial providers of personalized health records.
- b. **Health Passport System:** Currently utilized successfully in the foster care system.
- c. **Medical Home:** One of the functions of a Medical Home is to provide a place where up-to-date and comprehensive medical records are kept on current and past medical issues. Medical Homes can only be established with the cooperation and endorsement of DSHS and health providers state wide.

Recommendations for Sharing Specialized Knowledge

DDD should collaborate with the Developmental Disabilities Council to advocate for the inclusion of education and training to the following individuals involved in the health care system. Education and training should be supported in part by an infrastructure for health care management, and should include:

- A. Formal Education Opportunities provided through
 - **Incorporation of the unique medical care issues** of individuals with **developmental disabilities in medical, nursing and other allied health care professional schools' basic required curriculum.**
 - **Funding medical school residency programs** to provide education to residents on medical issues related to DD (didactic and practical).
 - **Continuing educational opportunities** for practicing health providers.
 - **Mini-fellowships** for health care providers to make available hands-on experience in providing medical care to individuals with developmental disabilities.
- B. Community Based Support for Health Care providers assured through
 - **A toll free number** to call for case consultation.
 - **Developing and recognizing resources in the community,** "Community Medical Referral and Resource Centers."
 - **Training** of hospital staff, physician office staff and emergency responders on how to work with individuals with developmental disabilities.

Recommendations to Measure Effectiveness

The task force believes that **measuring the effectiveness of health care is extremely important.** DDD needs to select items from each of four domains commensurate with the efforts of implementation to measure the effectiveness of interventions or select

measurable outcomes from Healthy People 2010. The following are the four domains of quality improvement:

- A. Structure:** The physical and administrative context in which health care is delivered.
- B. Process:** How health care is delivered and how things are done for an individual.
- C. Outcomes:** Measuring the impact or results of health care interventions.
- D. Satisfaction:** Measures feedback from the individual's perspective.

In summary, the task force recommends that the Division of Developmental Disabilities utilize the findings and recommendations of this document as the framework to implement changes to improve health care delivery for individuals with developmental disabilities. These changes should result in comprehensive, culturally competent, individualized, community-based health care including prevention and wellness. At the heart of these changes must be the individuals and their families.

III. METHODS

The task force met monthly with a facilitator. The information gathered was a result of literature searches, presentations, interviews and contacts with program representatives from around the country. The emphasis of the task force was on health and wellness of individuals with developmental disabilities.

The following people gave presentations to the task force during their monthly meetings:

Lauren Bertagna	Residential Contracts Team Region 4 DDD
Joelle Brouner	Communities Against Rape and Abuse (View of health care system from a consumer perspective)
Jane Campbell	Field Services Administrator Region 4 DDD (Structure of a Regional office within DDD)
Shan Shan Chien	Voluntary Placement Team Region 4 DDD (Health Care for children in foster homes)
Kari Cunningham-Rosvik	The Arc of King County (Health care issues facing adults with disabilities)
Mary Beth Ingram	Medical Assistance Administration (Medicaid eligibility)
Heidi Langlois	Adult Family Homes Team Region 4 DDD (Health Care issues for individuals in Adult Family Homes)
Jim Magee	Children Team Region 4 DDD (Health Care Issues for children residing with their families)
Kate Orville	Medical Home Leadership Project (Project overview)
Sue Potl	Division of Developmental Disabilities (Eligibility criteria and system overview)
Virginia Radel	Adult Team Region 4 DDD (Health care issues for adults)

The following programs and businesses were contacted for information:

New Mexico Continuum of Care
 Pennsylvania Special Needs Unit
 California Department of Developmental Services
 University of Wisconsin- Madison Medical School
 Northern Virginia Training Center
 Siemens (Computer based medical records)

Consultation with:

John Neff, M.D., Director	Center for Children with Special Needs and Chronic Health Conditions, University of Washington
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Various literature searches were conducted through the Washington State Library system and through the use of Internet search tools.

IV. INVESTIGATIVE REVIEW - KEY FINDINGS

1. General Review of Health Care Issues

According to the World Health Organization (WHO), health can be defined as a state of physical, mental or social well being; not merely the absence of disease or infirmity.* In the last 40 years, dramatic changes have been made in the lives of individuals with developmental disabilities due to an emphasis on normalization and inclusion, but the health status and health service needs of individuals with developmental disabilities have received very little attention.¹ Due to advances in medical and public health, the average life expectancy for individuals in the United States has increased to 76.5 years². The life expectancy for older individuals with mental retardation (MR) is 66.1 years but younger adults with mental retardation are expected to live as long as their peers without MR.³ Advances in public health, prevention and advances in treatment have helped in improving health status and life expectancy for all individuals¹. Unfortunately, the poor, the minorities, and the socially disadvantaged have poor health outcomes and lack of access to adequate health services.⁴

Individuals with developmental disabilities have more challenges in understanding and maintaining their health. It is estimated that only 42% of individuals with Mental Retardation/Developmental Disabilities (MR/DD) reported being in good health, as compared with 67% of those without MR/DD⁵. According to Jobling⁶, individuals with developmental disabilities experience more health problems throughout their lives than people in the general population. There is evidence in the literature that suggests individuals with developmental disabilities receive less medical care compared with the general population.^{7,8} It has been documented that individuals with developmental disabilities have four times more preventable mortality than individuals in the general population.^{9,10}

The quality of services received by individuals with developmental disabilities may not be optimal. For example, individuals with developmental disabilities have an increased prevalence of certain health conditions such as thyroid diseases, diabetes and obesity, and many of these conditions are not addressed by the primary care providers.^{7,8,11} Several researchers have noted that individuals with developmental disabilities do not receive preventive or health maintenance services such as annual health screenings.^{8,11,12, 13, 14}

A. When health care services are provided to individuals with developmental disabilities, health care providers face five main barriers according to a study by Lennox, et al.:¹⁵

- Communication difficulties in understanding and obtaining information from individuals associated with poor comprehension.
- Lack of good history due to poor documentation in the past. Health care providers not having significant knowledge of individuals' health concerns due to high staff turnover, or staff having poor understanding of symptoms.
- Lack of compliance with a medical management plan. Examples are lack of follow up and difficulty in following treatment recommendations.
- Physicians' lack of knowledge of medical conditions or illnesses common in people with developmental disabilities.

... purpose of health care system is to reduce burden of illness, injury and disability and to improve health status and function...

Individuals with DD have more challenges in understanding and maintaining their health

- Time constraint on the part of the physician. It takes more time to get a history due to many complicated issues and it takes longer to do an examination due to various physical disabilities.
- B. Another study reported three major obstacles in the following rank order¹⁶:
- Physician's ability to get information about the individual's presenting problem and medical history. The inadequacy of medical information was identified as the greatest obstacle to a physician's efforts to manage the care of an individual with developmental disabilities living in the community.
 - Maladaptive behaviors of individuals with developmental disabilities in the office setting. When individuals were uncooperative with a physical examination, only 20% of the physicians were prepared to cope with the situation.
 - Liability issues are of concern. More than half of the physicians did not know who was authorized to give consent for medical treatment.
- C. As succinctly summed up by Newacheck, "health care needs of individuals with developmental disabilities are not addressed adequately due to the lack of a knowledgeable care provider and continuity of care, as well as limited resources in the community."¹⁷
- D. According to Surgeon General Satcher, many doctors and dentists won't treat Medicaid patients because of unrealistically low reimbursement rates. Others are "not comfortable in treating people with mental retardation", he added.³⁷

2. General Review of Issues Related to Education of Health Care Providers

The Special Olympics Report of 2000¹ states the following issues: National and international research suggests that primary care providers often lack training on how to communicate with individuals with developmental disabilities. They may lack knowledge of the specialized medical, preventive, and social service needs of individuals with developmental disabilities or the available community resources and supports for this group of individuals.¹ Additionally, providers are interested in broadening their knowledge to improve services for individuals with developmental disabilities. The lack of training and experience in issues related to the developmental disabilities population is a factor in a provider's willingness to provide treatment to individuals in this population. It is also reported in literature that health care providers have negative attitudes and very often stereotype individuals with developmental disabilities regarding their ability to maintain their health status.¹ It is documented that coordination between primary care providers and specialty services is also very poor which leads to poor quality health care.¹

Physicians make value judgements about the worth of individuals with mental retardation in making diagnoses and treatment decisions, and may withhold treatment or referral to a sub-specialist.^{18, 1} A survey of providers has indicated that physicians have lower expectations and more pessimistic views of the abilities, or the potential, of individuals with developmental disabilities than do family members or other professionals.^{19, 20, 21}

The following is an excerpt from the summary recommendation (Health Status and Needs of Individuals with Mental Retardation, 2000 Report submitted for Special Olympics)

One reason that the health care system does not adequately provide care to individuals with MR is that providers (e.g., physicians, nurses, psychologists, ophthalmologists) do not feel equipped to treat them. The curricula and training for all health care providers should be reviewed and updated to include specific education on MR. This should include not only classroom hours, but also clinical experience with this population.

Guidelines help to ensure the quality of care and raise providers' confidence that they are providing appropriate care. Specific screening and health supervision guidelines should be developed for individuals with MR addressing their special health care needs.

Through research of the types of specialized education available to health care providers on the health issues unique to individuals with developmental disabilities, the task force found very few comprehensive programs in the United States. Several states developed programs to educate health care providers about the health care needs of individuals with developmental disabilities in response to the closing of large state run facilities. At that time, there became an urgent need to provide health care to individuals with complex health problems in the community. Following are examples of educational components in three states. Additional information is contained in Sub-section 4, "Examples of Systems/Infrastructure in Selected States".

California: Specialized curriculum for medical students, mini-fellowships, continuing education opportunities, website and 24 hour help line to field questions from health care providers;

New Mexico: Specialized curriculum for medical students, residency training, and traveling teams to educate and consult, on site training seminars, continuing education newsletters, and on-line resources;

Wisconsin: Specialized curriculum for medical students, including spending time in a home with a child with special care needs, seminars for residents, conferences for practicing physicians, and resource for individuals with developmental disabilities and their families/support staff in dealing with health care providers.

3. Review of Issues Related to Health Care Records

Additional excerpt from the summary recommendation (Health Status and Needs of Individuals with Mental Retardation, 2000 Report submitted for Special Olympics)

Providers are often ill prepared to treat individuals with MR because patients may not be capable of describing their medical histories, and the medical record system is not equipped to provide such information. The record system is in need of reform in order to address the lack of continuity of care received by this population. One way to do this would be to initiate a health passport system where individuals with MR and their caregivers keep an ongoing record of their care and are able to present it to their provider at each visit." Sir William Osler said, " Listen to the patient, he is telling you the diagnosis." This fact is still true - patient history plays a major role in helping clinicians reach a diagnosis. Individuals with DD generally have difficulty

Insufficient documentation has been found to be one of the obstacles to quality medical care.

...health outcomes are compromised because of insufficient tracking systems.

...health care needs of individuals with developmental disabilities are not addressed adequately due to the lack of a knowledgeable care provider, continuity of care, as well as limited resources in the community.

According to Surgeon General Satcher, many doctors and dentists... are "not comfortable in treating people with mental retardation"

communicating their medical history and symptoms to the physicians and they rely on family members or care givers. Due to high turnover in direct care staff, valuable information is often lost and/or not communicated to the health care provider. For persons with multiple health related disabilities sometimes individuals receive primary and specialty care in different locations and the information is not well communicated between providers which results in duplication of care as well as fragmentation in care and perhaps incomplete therapeutic effort and follow through.²²

Personal health records are often created and maintained by individuals or by caregivers. Usually they contain a list of medications, a summary of health conditions, known allergies, and a history of immunization. Medical records are kept in physicians' offices and generally patients don't see them. Some physicians' offices keep these records on paper - others are kept electronically.

Examples of Paper Based Records

The following examples are described in detail in *Appendix 1*:

1. In California, an example of paper based personal health records is the "*Health Education Awareness Resource Tool*" (H.E.A.R.T Journal). This tool was created for individuals who do not require many support services. Initially, the individual works with an advocate to complete personal information, health care provider information, insurance information, special medications, communication needs and physical limitations. The individual takes this tool to all medical and dental appointments for health care providers to update the information on all aspects of their health.
2. MCare '*Taking Charge of my Health Tool Kit*' has tools for individuals with disabilities who want more say in health care services. (MCare is the national clearinghouse on long-term supports and services for individuals with disabilities and their families at the Institute of Disability, University of New Hampshire). The Tool Kit has the following items:
 - "Listening to Me and Building on My Strengths"*
 - "A Tool to Assist Individuals with Disabilities in Planning Positive Outcomes from their Health Care Services"*
 - "A Tool to Assist Individuals with Disabilities in Communicating with their Health Care Provider"*
 - "Quick Check"*
3. PACER Center (Parent Advocacy for Educational Rights), has two useful check-lists:
 - "Health Care Skills." This form has a five level grid for 25 questions to assess an individual's health care skills.
 - "Health Care Check list for Residential Setting." This is a 16-point questionnaire to ask how health care issues are dealt with by a residential care provider.

Advantages of Paper Based Medical Records ²⁷

- Flexibility of input.
- Often dictation/transcription is the fastest and easiest method to input information into the medical record.

- No or very little initial startup expense.
- No special training required.
- Something that people are used to and familiar with.

Challenges with Paper Based Medical Records

- Inflexibility of data retrieval.
- Access to information limited to one person at a time.
- Some risk to confidentiality; staff in an office can view it when filing and storing.
- Paper storage and transfer costs.
- Legibility issues, especially handwriting.
- Lost records.

Examples of Computer Based Records

An average person visits his or her primary care physician, specialists, emergency room doctors and hospitals, etc., three to five times per year¹. Each physician encounter is documented, including medical history, test results, list of medications, x-rays, EKGs, and reports of other procedures. For an individual with multiple specialists and multiple chronic problems, the bulky paper-based charts are transferred from one office to another or summarized by providers. When computers became commonly used in hospitals, physicians started to use them to streamline some of the processes. Now, health information is available through the Internet to patients as well as physicians.

There are two types of computer based record systems: proprietary electronic medical records and web based medical records.

1. Proprietary Electronic Medical Records

These are available to each practice or group of physicians. The records are accessible remotely through a private network. Usually there is a significant start-up cost for software, hardware, and staff training but they offer many advantages over paper-based systems:²⁷

- Reduced time spent in retrieving the records.
- Confidentiality is maintained by password protection. They are more private than web based because data is stored in a private server and accessed through secured channel.
- Reduced cost of storage compared to paper based.
- Reduced reliance on patient to provide history of past medical issues.
- Capability of tracking patterns, analysis of longitudinal data leading to better decisions.
- Potential to reduce redundant testing.
- Automated ticklers to remind follow-up.

They have the following problems:

- Lack of compatibility among primary care physician's electronic medical records, hospital electronic records and/or sub-specialists' electronic records.

- Lack of universal vocabulary (history/physical).
- Free text input slower than dictation, structured documentation inflexible.
- Unwieldy decision trees.
- Very expensive to purchase and support.
- Lost records.

2. Web Based Medical Records:

There are two major types of medical records available on line:

Patient records created and maintained by individual patients or caregivers

These sites contain information about the patient's personal history, past medical problems, allergies, and medications. These records help the patient communicate with his/her physician effectively as the data can be printed and taken to the appointment or the doctor can be provided with a password with which he/she can access the Internet records. This method can be extremely useful in an emergency when a patient is unable to communicate.

"Patient Empowerment" is the core of patient centered practice of medicine and web based systems provide more opportunities for patient involvement. The knowledge and resources to maintain the system are extremely important. The patient and/or caregiver are responsible to update his/her record after each visit to a provider or send them to the vendor for update.

Medical records managed by physicians and/or their staff

The physicians enter the progress notes, diagnosis, treatment plan, tests prescribed and results, medications, and follow up plans. Some of these programs will allow automatic communication with pharmacies and appointment scheduling. The information by specialists can be entered also and is available for everyone to utilize. The patient and physician can have access to these records at any time or any place where a computer with an Internet connection is available.²⁸

Advantages of Web based Electronic Medical Records²⁷

- Allows input by voice, typing or scanning.
- Allow multimedia (graphics, images, video sounds).
- More flexible interface with other medical record systems.
- Less expensive than proprietary.
- Centralized repository for trend analysis.
- Easier to navigate than proprietary electronic medical records.
- Accessible from various devices and at various locations.
- Patient-centric for optimal longitudinal care.
- Hypertext links to guidelines, journals, and other knowledge sources.

Challenges of Internet Based Patient Records^{27, 29}

- The physician may not consider the information provided by a patient to be an accurate medical record. They may read it but may not consider it authentic.
- Privacy: According to a JAMA article³⁸, "Computerized databases of personally identifiable information may be accessed, changed, viewed, copied, used, disclosed, or deleted more easily and by more people than paper based records."

Privacy of medical records is very important and is considered a major barrier to widespread use of computerized medical records. Among 37 million online users, only 6.3 million (17%) use online health information primarily because of privacy and security concerns.³⁹ Most sites provide assurances that the personal medical information is protected and is not shared by unauthorized people. Such statements have not convinced many people because they see secure sites that are sometimes hacked. Many sites now claim that identification numbers are required which are sent over the Internet in an encrypted form and most systems encrypt their databases making it more difficult for hacker attacks.

- Security risks of unauthorized use such as linking it to employment data or inappropriate use by secondary parties.
- May be less technically reliable; the data is stored on a server that you don't own.
- The data is patient centric; questions of data ownership and liability may become an issue.
- Clinicians are reluctant to use eHealth tools because of perceived drain on time, legal and liability issues, and lack of reimbursement.⁴⁰
- There is a gap in computer and Internet access among certain population groups when segmented by income, educational level, race/ethnicity and disability. Persons with a disability are half as likely to have Internet access as those without a disability. Socioeconomic factors are considered main reasons for the digital divide.⁴¹

4. EXAMPLES OF SYSTEMS/INFRASTRUCTURES IN SELECTED STATES

The task force reviewed the health care provider education programs and health records systems in various states and found that they were usually integrated into a system infrastructure for health care for individuals with developmental disabilities that covered either the entire state or a specific geographic area of the state. The following are examples of systems identified by the task force that meet the health care needs of individuals with developmental disabilities in a unique manner.

CALIFORNIA – Wellness Initiative

Enhancing Physician Knowledge and Expertise in Developmental Disabilities

- A. Medical School curriculum: UCLA has a program for the Medical School curriculum focusing on developmental disabilities courses for medical students including training of faculty members.
- B. Physician Assistance, Consultation and Training Network: This program is available and free to all physicians in California serving people with developmental disabilities and offers 24-hour response time for calls received during business hours. The purpose is to provide consultation to physicians on specific patient concerns in various specialties.
- C. Mini-fellowship in Developmental Disability: Mini-Fellowships are offered to physicians practicing in California by UC San Diego and San Diego Children's Hospital and Health Center. Physicians are only charged a nominal administrative

Computerized databases of personally identifiable information may be accessed, changed, viewed, copied, used, disclosed, or deleted more easily and by more people than paper based records.

fee because the cost is supported by a grant. Physicians can claim up to 48 hours of continuing education credits depending upon the actual time spent in various activities. In addition to earning CME credits, the community physicians work with experienced specialists to become more confident in taking care of children and adults with developmental disabilities and to learn new advances in this field. Interested physicians can schedule this educational opportunity based on their interest and choose from various options.

- D. Continuing education activities for physicians and medical professionals: Each Region develops its own training to educate physicians and other medical professional on issues related to developmental disabilities.
- E. Other educational resources:
 - Website and links to educate providers
 - State of California Programs and information
 - Medical information and research
 - Information on specific medical conditions
 - Issues related to DD
 - Early intervention referrals
 - CD ROM tutorials
 - Video tapes
 - Listing of expert speakers

NEW MEXICO – Continuum of Care

Enhancing Physician Knowledge and Expertise in Developmental Disabilities

- A. The Medical School Curriculum includes education in Developmental Disabilities.
- B. Residency Training - The continuum buys a day in various residency-training programs to help pay the stipend to Residents in Pediatrics, Family Practice, Neurology and Internal Medicine. Family practice residents spend time with families and the families receive stipend to participate in this educational process.
- C. Travelling Teams: The purpose of travelling teams is to educate various practices about developmental disabilities and to provide services and consultation in remote areas.
- D. On-site training seminars to local physician practices: A team with expertise in developmental disabilities consisting of a pediatrician or family physician, neurologist, psychiatrist, and behavior specialist works with physician practices. This service is advertised in various professional publications and is available to any practice. The travelling teams provide financial support to the practices to defray the cost of not seeing regular patients that day. The training is done in two parts: the morning session is didactic; discussion with practical training is provided in the afternoon. The local physician and the travelling team see the individuals with developmental disabilities together. All staff participate in training and any specific issues important to their areas are covered. The goal is to maximize benefits to individuals with

developmental disabilities, physicians, and their staff. The main components of training include:

- Prevalence of developmental disability.
 - Seizure disorder considerations in patients with developmental disabilities.
 - Psychiatric consideration in patients with developmental disabilities.
 - Early signs of developmental delay and early intervention.
 - Periodic monitoring of various disabling conditions.
 - Impact of disability and/or chronic conditions on daily living such as school, work, family, emotional health and social life.
 - Coordination with specialists, schools and community programs.
 - Compliance with ADA in health care settings.
 - Record keeping considerations.
 - Strategies for gaining cooperation from fearful/resistant patients.
 - Adult medicine, neurology, and psychiatry clinics in remote areas.
- E. To help them understand the health needs of individuals with developmental disabilities, training is provided to interdisciplinary teams, families/guardians, and community residential providers, including paramedics, local hospitals, and schools.
- F. Local Champions: These are clinics and physicians in various communities who are willing to help health care providers in their community. These Local Champions receive training and stipends to keep abreast of new developments in the field.
- G. A quarterly newsletter is mailed to all physicians in New Mexico. This newsletter contains relevant topics related to developmental disabilities that could be of interest to physicians providing services to individuals with developmental disabilities.
- H. Continuing medical education on best practice guidelines.
- I. On line resources:
- A Health Manual containing information regarding specific chronic conditions, mental health issues, and congenital syndromes.
 - An interactive tool providing medical information on wellness management, strategies to help make the most out of routine and emergency doctor visits, and pharmacy visits.
 - Protocols on end-of-life decisions, dysphagia and nutritional management, etc.

PENNSYLVANIA - Infrastructure

In Pennsylvania, 70,000 children and adults with mental retardation live in the community. Pennsylvania has two state systems to address individuals with developmental disabilities; one system serves individuals with mental retardation, and the second is a

special needs unit which serves individuals with developmental disabilities but who have normal intelligence.

In Pennsylvania, Medicaid clients are served by Managed Care Organizations. They believe that managed care provides two main sets of benefits: improved access to health care, and better quality assurance. Managed Care Organizations are required to use indicators related to quality of care.

In 1997, Pennsylvania designed the Health Care Assessment Initiative to collect health care information. The goals were to ensure optimum health care for people with mental retardation living in the community and to assist with building community capacity to improve health care. A Health Risk Assessment (HRA), a 21-page evaluation instrument, was developed as a measurement tool. HRAs were completed on 600 people and a repeat assessment was done 18 months later. The HRA is an instrument that provides population-based data, and has the following main components:

- Access to health care (primary care, dental care, and specialty care).
- Participation in wellness and prevention, e.g., smoking, weight reduction, etc.
- Disease management, assessment of prescribed medications and their appropriateness to the diagnosis and side effects.
- Supportive equipment assessments, e.g., glucometer, walker, wheelchair, etc.

Health risk profiles were done on randomly selected individuals. Those individuals were assigned risk levels (high, needing monthly visits by medical personnel; medium high, needing five to six visits a year by medical personnel; medium, needing two to four visits a year; medium low and low). Systems changes were made to develop the medical infrastructure.

Health Care Coordination Units (HCCU) were developed in counties to facilitate overall health care services to people with mental retardation (MR). Each HCCU is staffed with four to five positions (nurse coordinator, part-time MD, psychiatrist, and social workers). In addition, each has field clinical staff (five to seven) consisting of RNs (approximately one RN for 150 individuals). Each HCCU is responsible for doing physician education, coordinating health care with specialists and hospitals, and training of direct care staff and families. The program is funded by state and federal match and is administered by the counties.

WISCONSIN – Initiative for Physician Education

The Wisconsin DD Council originally funded the University of Wisconsin Physician Education Project on Developmental Disabilities. This project is now a continuing program of the University of Wisconsin Department of Family Medicine. It is a multi-dimensional approach to improve the quality of care provided by physicians to children and adults with developmental disabilities.

- A. Medical Students: During the first three years of medical school, each student at the University of Wisconsin Medical School participates in a formal curriculum on family centered care and developmental disabilities. The students learn about functional assessment, parent/professional collaboration, interdisciplinary team communication, and care coordination. They learn about specific types of disabilities. Additionally, there is a practical component. In the first year, students spend an evening in the home of a family that includes a child with special care needs. In the

second year, students learn about functional assessment during their course in physical diagnosis by interviewing and examining individuals with developmental disabilities. In the third year, they do intensive community based case study on a child or adult with a chronic illness or disability utilizing a family-centered approach.

- B. Family Practice Residents: Seminar presentations are given to residents on topics related to developmental disabilities. All residents follow individuals with developmental disabilities in their model practice and receive individualized teaching about the medical care of those individuals on a regular basis during their Madison Family Practice Residency Training program.
- C. Practicing physicians: The Department of Family Medicine developed presentations consisting of the same topics as given to students and residents that are now being provided to practicing physicians. Daylong conferences on issues related to the medical care for people with developmental disabilities have been organized for community physicians. The University of Wisconsin also provides case consultations in individual situations as needed by community physicians.
- D. Consumers: A program "Diagnosing Doctors" has been developed. Specialized training is provided to the individuals with developmental disabilities, and their families and staff supporting them during the training. They learn to analyze specific problems they encounter with physicians and learn to apply specific intervention techniques to resolve conflicts. These presentations have been given in Wisconsin and also nationally and have enhanced the services for individuals with developmental disabilities.

VIRGINIA

In 1996, Virginia made a decision to develop a Center for Excellence at Northern Virginia Training Center (NVTC). As a Center for Excellence, NVTC can be a part of the continuum of care for persons with mental retardation and serve as an integral resource for the community to provide needed medical, behavior, and dental services sharing facility staff expertise and training community staff.

NVTC developed and implemented a pilot program called the Regional Community Support Team. The following is a summary of the Regional Support Team's main activities:

- The Northern Virginia Health Care Issues Survey was completed.
- The survey indicated that a large percentage of consumers could not easily access community-based physicians or medical specialists to sufficiently meet their health care needs.
- Other individuals in the community may have adequate health care, but when seen by Regional support teams it was evident that they demonstrated a need for multiple and complex services, including sophisticated nursing supervision and medically oriented case coordination and management.
- The pilot was successful and now a Regional Community Support Center is funded to provide services to the individuals who live in the community, with some services provided at NVTC and some services provided in the individual's homes. In addition to clinical services, training and education is also provided to the community providers.

There is a lack of health care providers knowledgeable about health care issues for adults with developmental disabilities.

Providers don't have time to educate individuals or families regarding wellness and prevention.

5. REVIEW OF ISSUES IN WASHINGTON STATE

A. Barriers to Health care for people with developmental disabilities were identified by the task forced based on brainstorming sessions:

a. Access

- There is a lack of health care providers knowledgeable about health care issues for adults with developmental disabilities.
- Individuals with developmental disabilities and their families lack sufficient knowledge to get into the DDD system.
- Individuals with developmental disabilities may access care in non-traditional ways, e.g., calling 911.

b. Records and Information

- Some individuals do not have family members or caregivers to assist in gathering information. Due to a lack of a historian, the details of medical history are not available and useful information is lost.

c. Provider's Issues and Fiscal Constraints

- Many health care providers do not accept Medicaid because of low reimbursement rates. Financial barriers are even more significant for the providers in small towns - either they have to see a high volume of individuals with developmental disabilities or limit the number of patients with developmental disabilities.
- Health care providers are sometimes unwilling to accept clients with developmental disabilities due to a perceived stigma and impact on their practice.
- Health care providers lack training in dealing with individuals with developmental disabilities.
- It takes more time to provide care to an individual with developmental disabilities and the reimbursement system does not account for the added time.
- Health care providers are sometimes reluctant to authorize standard screening tests because of low reimbursement rates under Medicaid.
- Health care providers don't have time to educate individuals or families regarding wellness and prevention.

d. Issues unique to individuals with developmental disabilities

- Some individuals with developmental disabilities do not have the ability to communicate and have difficulty understanding all of their health care issues, long term consequences, and follow through.
- There are an increased number of aging individuals resulting in more chronic medical issues.
- The community standard for health care is probably insufficient to address the needs of individuals with developmental disabilities because of their unique medical issues.
- There is no information on the health status or health needs for 9% of the individuals with developmental disabilities who do not have health insurance.

- There are instances when individuals are not eligible for DDD services or not identified.

B. Committees and Task Forces in the Past

COMMUNITY HEALTH SERVICES ACCESSIBILITY PROJECT

The project was sponsored by the Washington State Developmental Disabilities Planning Council in 1992.

- The report cited problems in maintaining medical records. Medical history was lost when individuals moved from one residential setting to another. Some caregivers felt they were able to facilitate effective and efficient physician- patient interactions, but many were not able to serve that function well. To address the issue of adequate health care information, a standardized chart was developed.
- The report recommended, "Sponsor the development of a modification of a video tape and training manual for use by the Departments of Internal Medicine and Family Medicine, University of Washington School of Medicine." One of the findings of this demonstration project was "the University of Washington School of Medicine, Departments of Internal Medicine, Family Medicine and Pediatrics needs to include, in their curricula, issues related to caring for persons with developmental disabilities and autistic-like behavior. These discussions have been initiated on a favorable note but funds are needed to modify the existing videotape and training manual so they will be acceptable to physicians and medical students. Discussions with the Schools of Nursing and Dentistry to ascertain the use of appropriate training materials for their students and post graduates should also be pursued."

In 1990 a task force (Developmental Disabilities Task Force) was supported by the Department of Community Development, State of Washington

- The report addressed the enhancement of the clinical skills of physicians caring for individuals with developmental disabilities. It was considered necessary and could be done by offering continuing education courses and clinics through the University of Washington and other organizations that have expertise the developmental disabilities area.
- The study demonstrated the need for improvement of record keeping of health care and mental health. It was the opinion of the project director that "the record situation deserves high level evaluation without delay."
- One of the five recommendations from this task force was: "A system for keeping accurate, complete health care records for DD clients is required. It should contain documentation of medical, dental and mental health care as well as the identity of those providing the services".

C. Systems in Washington State to Address Health Needs of Individuals with Developmental Disabilities

a. Developmental Disabilities Council Health Care Project

The record situation deserves high level evaluation without delay."

...a medical home is care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate and culturally competent, in which primary care physicians share responsibility.

Health Professional Training (project dates 2/1/99 to 4/30/02) - The Council has contracted with University of Washington, Center on Human Development and Disability to provide this training. The health care professional training curriculum was developed in year one, and has been modified for physician assistants and family practitioners. The curriculum was presented at various health care professional conferences and around the state. Additional providers, self advocates and family members in rural and urban area of state were surveyed to identify barriers to receiving quality health services for people with developmental disabilities and to provide input on the curriculum. Providers and family members will receive training in future years.

- Public Health Nurse (project dates 10/11/99 to 6/30/01) - The Council funded a Public Health Nurse project with the Quileute Tribe to improve access to and coordination of health, education, and social services for children with developmental disabilities, and their families, living on the reservation.

b. Medical Home Leadership Project:

A limited number of Medical Homes have been established in Washington State and it is a goal to have these resources available to all children and adults with developmental disabilities in the future.

As described in the American Academy of Pediatrics policy statement, a Medical Home is care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate and culturally competent, in which primary care physicians share responsibility. Care is provided by a well-trained physician who has the family's trust with care usually delivered in the physician's office rather than in an Emergency Room or walk-in clinic. The Medical Home should provide the following services:

- Preventive care including but not limited to immunizations, growth and development assessments, necessary screening and patient and parental counseling about health and psychosocial issues.
- Assurance of ambulatory and inpatient care 24 hours a day 7 days a week.
- Continuity of care.
- Identification of the need for sub-specialty consultations and appropriate referral. Provision of medical information to patient and consultant. Evaluation of consultant's recommendations and implementation including interpretation to the family.
- Interactions with school and community agencies to assure that the special health needs of the individual are being addressed.
- Maintenance of central record and database containing all medical information about the individual including information about hospitalizations. The record should be readily accessible and confidentiality should be assured.

Whether physically present or not, the physician directs all health care and acts as the individual's advocate, assuming control and ultimate responsibility for all health care.

- d. *The Medical Home Initiative for Children with Special Care Needs* has a goal that by 2010 there will be a medical home for every child. There are checklists to assess the primary care physicians' offices to ensure all components of a medical home are present.

V. RECOMMENDATIONS RELATED TO TASK FORCE CHARGE

Based on the information collected, the task force concluded that medical care provided to individuals with developmental disabilities is fragmented, isolated, and not easily accessible. Racial, ethnic, and cultural disparities also exist. There is paucity of medical knowledge of issues that are unique to developmental disabilities. There is a lack of emphasis on prevention and wellness.

The task force recommends that the Division of Developmental Disabilities choose one or more of these options for implementation along with our recommendations for better health monitoring options, and for sharing knowledge and expertise with health care providers. Following are task force recommendations in order of priority and are not mutually exclusive.

1. Recommendations for Systems Infrastructure Person Centered Health Delivery

A. Medical Home for Everyone

All individuals with developmental disabilities (children and adults) need a Medical Home/care coordination for stable and continued medical care.²²

Currently, a Medical Home Leadership Project is in existence in Washington State for children with special health care needs.

There is a resolution at the federal level that has a goal to have medical homes for all children with special health care needs by the year 2010. Such a system is needed for adults with developmental disabilities as well.

- Under this system, the physician, nurse practitioner (ARNP), physician assistant (PA) or other medical staff in a clinic or physician's office would be responsible for longitudinal care and over-all coordination of health care.
- This clinic or other health care provider would deliver routine, emergency, and preventive care and would be responsible for arranging sub-specialty referrals and or hospitalizations.
- The Medical Home provider would be responsible for communicating and coordinating health issues with all community based services such as work sites or schools.
- A Medical Home would maintain up-to-date and comprehensive medical records on current and past medical issues. This medical information should be accessible to health care providers and confidentiality would be assured.
- One way to generate interest in Medical Homes is to offer a monthly incentive to providers. The savings generated due to improved preventive care and care coordination would neutralize the cost.

- Trust between the Medical Home and the individual with a developmental disability and his/her family member or support staff is an integral part of this system.

The primary responsibility for implementation of Medical Homes would rest with the Secretary of DSHS in partnership with other state agencies, community providers, advocates, families and individuals with DD.

B. Health Coordinators/Person Centered Health Planning

It is critical that either the individual with developmental disabilities or his/her family and care giver has the necessary training and knowledge of the individual's medical issues to collect data, monitor side effects of medications and identify early danger signals. Pennsylvania uses such a system very effectively and they have shown improvement in the health status of individuals with developmental disabilities in their state.

- Each individual would have an Individual Service Plan (ISP) with medical alerts.
- Health care coordination would be provided by registered nurses or other medically trained staff and consists of medical care management services specifically tailored to the needs of the individual.
- The care coordinator would serve as a resource to the Case Resource Managers.
- Care coordinators would be responsible for ensuring that individuals have a primary care provider and necessary referral to sub-specialists to manage the complicated medical issues, therapies, transportation for medical appointments, coordination of medical information, and assistance with adaptive equipment needs.
- The care coordinator would also identify and work with other existing resources and entities such as Public Health Department, etc.

DDD would need to take primary responsibility for implementation of the creation of a system of Health Coordinators for person centered health planning.

Population Based Health Delivery System

A. Centralized Statewide Support System

A central support system could coordinate the Regional Medical Resource Center (RMRC) or act as a sole health care resource at the state level without a Regional system. The functions would be to:

- Develop and coordinate curriculums for medical, nursing, and other allied health schools.
- Provide a toll free number for assisting health care providers with specific medical issues related to developmental disabilities.
- Maintain a web site with resources for health care providers, individuals, and families.

- Serve as a resource to health care providers, residential providers, and families.
- Support clinics serving individuals with developmental disabilities.
- Educate and train individuals with developmental disabilities, families, and care givers about wellness and prevention.

DDD would hold primary responsibility for implementation in partnership with the Developmental Disabilities Council.

B. Regional Medical Resource Center

Within designated geographical areas, a RMRC should exist to coordinate medical care for the individuals with developmental disabilities in that region. Functions of each RMRC would include:²²

- Referral assistance for care of individuals' medical needs.
- Coordination of specialty referral. For example, Orthopedics, Neurology, Podiatry, Gynecology, Physical Medicine, and Psychiatry, etc.
- A system to ensure that medical records and necessary data are accessible to all providers involved in the care and coordination of medical issues.
- Training programs for primary care providers, community nurses, clinics, hospitals, and emergency medical response teams.
- Coordination with the University of Washington and community hospitals for residency training programs in Internal Medicine, Pediatrics, Family Medicine, Neurology, and Psychiatry.
- Outreach, onsite consultation and training to the residential care providers and community based services such as work sites or schools.
- Coordination with Medical and Nursing Schools and other allied health schools to provide opportunities for practicum training.
- Supporting local clinics that provide services to individuals with developmental disabilities.
- Assisting medical practitioners needing help by linking them to those clinics.
- Based on the needs of a particular region, especially in rural areas, out reach by the traveling teams specializing in providing care. The traveling teams could assist primary care providers by consulting and by providing training. Some regions might use "tele-health" using Internet technology to utilize the expertise of University of Washington or other experts outside of Washington State.
- Training to individuals with developmental disabilities, families, and caregivers on wellness and prevention.
- Utilization of Residential Habilitation Center Staff expertise to provide the following:
 - Training to community health providers regarding unique health issues related to individuals with developmental disabilities.

- Support a toll free number to assist in responding to health related inquiries.
- Outreach services to individuals in areas of Occupational Therapy, Speech Therapy and Adaptive Technology, etc.
- Education and training to individuals with developmental disabilities, their families, and caregivers on health related issues.
- Health care treatment of individuals with developmental disabilities who cannot find or afford a community health provider and assist in connecting them with a community provider.

The responsibility for implementation of Regional Medical Resource Centers rests with DDD.

2. Recommendations for Medical Records

In order to maintain consistency and ensure availability of comprehensive medical information, the Division of Developmental Disabilities, in cooperation with Medical Assistance Administration, needs to implement a standardized medical chart for all individuals with developmental disabilities and some systems changes are necessary. The task force's recommendation is that DDD will choose one of the systems to improve the quality of medical records.

A. Standardized Medical Records

The following are the essential elements of a medical record system to monitor the health status of individuals with developmental disabilities.

a. A Standardized Medical Form that is simple and comprehensive should be maintained for each individual. The essential components of records need to include:

- Medical History (family history, history of past illnesses/hospitalizations).
- Current medical diagnosis and medications.
- Prevention/Wellness (history of immunizations, general considerations such as smoking, weight reduction, etc., and specific issues such as thyroid function for people with Down Syndrome, etc.).
- Screening tools as appropriate to age and as determined by standard practice for the general population, including, flu shots, Pap smears, prostate exams, mammography, etc.
- Checklist for each medical appointment.
- Management plans for chronic health conditions. Examples might include:
 - Seizure disorders
 - Respiratory problems
 - Swallowing or eating disorders
 - Mobility/positioning problems
 - Behavior/mental health issues

b. An identification card with a summary of medical information: Each individual should be provided with a wallet size card or a medical alert bracelet summarizing essential information about the individual including, but not limited to:

- Allergies;
- Name and telephone number of primary care physician;
- Name of family member or other emergency contact;
- Medical Alerts (Seizures, Diabetes, etc);
- Other relevant medical information.

c. Other important issues related to Medical Record System

- Confidentiality must be maintained. All personal information should be safeguarded.
- Information about past medical problems, family history, past medication use, information on communication and physical limitations, and allergies should have to be entered only once and should be available to all health care providers.
- Laboratory tests and diagnostic tests ordered by one provider should be available to all providers.
- List of current and past medications including allergies.
- Entire medical information should be available to emergency medical providers easily and quickly.
- All information should be easily accessible to the individual with developmental disabilities and their family and care givers so they can actively participate in the management of medical problems, prevention, and wellness.
- Reminders for prescription refills and medical appointment are not essential but extremely useful.

DDD should lead the effort to incorporate the expertise of medical providers in establishing the essential elements of any medical records system.

B. Health Records Systems

The following three ways are recommended to ensure that health records are readily accessible to health care providers:

b. Health Passport System

The individual with developmental disabilities, their family members, or caregivers would keep an ongoing record of issues related to health care. The information would be recorded in this passport. Each health care provider would submit a copy of test results, medical exams, and treatment plans. The individual, family member, or caregiver would be responsible to keep this

passport updated. This passport would be taken to every medical appointment. The preparation for an appointment is recorded in this passport and information after an appointment is updated in this passport. This information could be kept in a three ring binder, accordion folder, or stored on a floppy disc. The standard health care form can be put on a DDD website and downloaded, or a paper version could be available for individuals, family and caregivers. The essential elements of a chart need to be as described in Section A. By having all the medical information contained in the passport, duplication of tests or other procedures can be avoided. It would also preserve the medical history when individuals access medical care from various specialists or other health care providers, therapists, or in an emergency situation. (See example: Children's Services Passport system for Foster Children).

a. Web based Medical Records

The standard chart as described in Section A could be kept on the World Wide Web. DDD could contract with one of the commercial providers of web based health records or build their own database. The advantage of contracting is that no resources would be needed to keep up the database but it would cost approximately \$20 -\$25 per year per person. Web based medical records have most of the characteristics of an ideal medical records system as described above. These records could be used as consumer health information management tools and might have following uses:

- To provide a means for health consumers to manage their own health data by providing tools for consumers to collect, monitor, trend and disseminate their own health data.
- To provide education and linkage to health information sites.
- To provide access and data exchange between the consumer in the community and health care professionals in a variety of health care facilities.

c. Medical Home for Children and Adults

One of the main functions of Medical Home is communicating and coordinating various health issues with other health care providers. The Medical Home is also a place where up-to-date and comprehensive medical records are kept on current and past medical issues. The data is easily accessible and confidentiality is assured. (See details in #3 under Systems).

DDD must decide which of the identified three ways are most appropriate to ensure that health information is readily and easily accessible to health care practitioners. Implementation requires the assistance of the DD Council and other DSHS offices' expertise.

3. Recommendations for Sharing Specialized Knowledge

Health care providers need to be knowledgeable in two main areas: 1) technical knowledge about various syndromes and medical conditions that are more common in individuals with developmental disabilities, special screening tests necessary, and effective treatment modalities, and 2) awareness in communicating with individuals, families and caregivers, and sensitivity to the issues in the lives of individuals with developmental

disabilities. Individuals with developmental disabilities are sometimes unable to cooperate with medical examinations and treatment and supportive measures are necessary. Having empathy and understanding of the unique issues related to individuals with developmental disabilities is very important to be effective in providing care and treatment.

A. Formal Education Opportunities

a. Students in Medical, Nursing, and Allied Health Profession Schools

The curriculum should include medical care for individuals with developmental disabilities. The University of Washington School of Medicine, Nursing and allied health professional schools need to include health issues related to care for individuals with developmental disabilities. Financial commitments to develop the training materials and changes in curriculum are necessary to address the specific needs of medical, nursing and allied health professional schools. Discussions with the Dean of the Medical School and other Department Heads need to be started and followed up to ensure there is support for inclusion of developmental disabilities issues in these curricula. These types of changes would need commitment, perseverance, and patience.

In addition to physicians and sub-specialists, other professionals providing care to individuals with developmental disabilities need the training in specific issues unique to individuals with developmental disabilities. Some examples of such professionals are ARNPs, PAs, physical and occupational therapists, speech therapists, podiatrists, optometrists, dietitians, hospital staff, social workers, and emergency medical technicians, etc.

b. Resident Physicians

Seminars and presentations should be given to residents and interns on topics related to developmental disabilities. Residency and internship programs need to be funded so that every resident/intern spends time (one day to one week) dedicated to developmental disabilities issues. These issues include unique health care needs of individuals with developmental disabilities, family/care giver coordination, communication, interdisciplinary components, and roles of various community support systems. There are two parts of training: didactic and practical.

c. Continuing Medical Educational Opportunities for Practicing Physicians, Nurse Practitioners, and Physician Assistants

Continuing medical education opportunities need to be available. The Center of Human Development and Disability (CHDD), with a grant from Developmental Disabilities Council (DDC), have developed a program that has been presented to physicians and Physician Assistants. The same, or similar, program could be presented to other health care professionals. A daylong program could be organized with the University of Washington and CHDD for physicians practicing in the community.

d. Mini-fellowships

Health care providers could enhance their knowledge by working with University of Washington CHDD clinics or health care professionals in RHCs and interacting with DDD Case Managers and families. The mini-fellowship could be of variable duration and should have sponsorship from the University of Washington so that health care providers can get credit for continuing medical education. California currently offers such mini-fellowships at no cost to physicians interested in enhancing their knowledge in this field.

B. Community Based Support to Health Care Providers

- a. A **toll free number** for case consultations could be available with a commitment of a timely response. A similar program is currently available for various specialties through the University of Washington, “MEDCON”.
- b. A **web site** could provide resources to the primary care physician to address the unique medical care needs of individuals with developmental disabilities. The site would need to contain evidence-based information on etiology, diagnosis, and treatment of medical conditions faced by individuals with developmental disabilities including various congenital syndromes, chronic medical conditions, and wellness/prevention. The website could also offer information for family and care givers as well as for the individuals with developmental disabilities.
- c. **Resources in the community:** DDD would recognize local medical providers, clinics and medical centers in each community. These centers would help other providers, share expertise, and network with other health providers. These community resources would need support to gain and maintain knowledge and expertise in special medical issues related to individuals with developmental disabilities.
- d. **Support Staff and other professionals’ training:** Specific training should be provided to physicians’ office staff providing medical care to individuals with developmental disabilities in communicating, setting up appointments, learning to effectively work them during and after appointments, in waiting rooms, in examination rooms, and follow up. Training for hospital staff and other emergency responders on unique developmental disabilities related issues needs to be available.

e. Training of DDD Resource Case Managers, Residential Providers, and

Families

- Guidelines on preparing for medical appointments, questions to ask the doctor, facilitate communication during face-to-face visits, and how to be trainers for others.
- Data to be tracked to assist physician, e.g., seizures, weight. etc.
- Contingency plans to address crisis prevention; general issues and issues based on specific medical diagnosis or chronic medical condition.
- Guidelines to make health care decisions, individual’s rights on choice regarding advance directives and refusal for certain medical treatments.

The task force strongly recommends that DDD select items from each of these domains to measure the effectiveness of health care provided to the individuals with DD or select measurable outcomes from Healthy People 2010.

- An emphasis on prevention and wellness aspect of health. Examples might be programs to assist in meal selection and healthy nutrition, regularly scheduled exercise programs to motivate individuals to facilitate change in behaviors.

DDD should collaborate with the Developmental Disabilities Council to advocate for the inclusion of education and training to health care providers, allied health care providers, residential providers and families. Implementation requires the collaboration of schools of medicine, nursing, and a variety of specialized schools for therapies and ancillary services.

4. Recommendations to Measure Effectiveness of Care

Quality Improvement

There has been much discussion about quality in health care and the importance of the quality of care. According to the Institute of Medicine, “At no time in the history of medicine has the growth in knowledge and technologies been so profound.”³¹ For people with developmental disabilities, quality issues in health care are even more important as the impact of poor quality of care might be more deleterious to individuals with DD compared to those without disabilities.³³

Historically, clinicians relied on traditional biochemical measures such as laboratory tests to determine the necessary intervention and whether the intervention was successful. Researchers have discovered that when only these measures were used, health care providers missed many of the outcomes important to patients.³²

According to literature^{34, 35} domains of the four health care qualities are **structure, process, outcomes, and satisfaction**. Structure and process are external to the person while outcomes and satisfaction are derived from the person receiving services. **The task force strongly recommends that the Division of Developmental Disabilities select items from each of these domains to measure the effectiveness of health care provided to the individuals with developmental disabilities but select only those outcomes that are commensurate with the efforts and implementation.**

The domains are:

A. STRUCTURE is the physical and administrative context in which health care is delivered. Following are important elements of structure:

- a. Access to medical care
 - The services are available to individuals with developmental disabilities;
 - The services match the need of the individual;
 - The geographic location of primary care clinic, specialty clinic or hospital, is at a convenient distance from individual’s residence;
 - The provider accepts the individual’s health insurance coverage or payment.
- b. Comprehensiveness of care
 - There is availability of primary, secondary and tertiary care for individuals with developmental disabilities;
 - Primary care includes preventive care, health promotion, wellness and education;

- Scope of care is broad and includes neuro-developmental therapy such as occupational, physical, and speech therapy.
- c. Health Promotion/Wellness
 - Health promotion and wellness practices as they apply to the general population, e.g., smoking cessation, immunization, etc., are incorporated into regular medical visits.
 - Unique health promotion issues with individuals with developmental disabilities, e.g., physical fitness activities for a person with a physical disability, feeding program to prevent aspiration, etc., need to be a part of the primary health provider's regular screens at visits.
- d. Education in issues related to developmental disabilities
 - Continuing medical education activities or other training to stay current with new developments in the field of developmental disabilities is available through university medical or nursing school affiliations.
 - Training and education for individuals with developmental disabilities, family members, and other caregivers is offered in order to monitor changes in health status and to manage chronic medical problems.
- e. Policies and procedures of clinics and health care providers' offices
 - Training is provided to staff to assure appropriate interactions between staff and individuals with developmental disabilities, their family members, and/or caregivers.
 - Individuals, families and caregivers are included in decisions about health.

B. PROCESS is the way in which health care is delivered for the individual receiving services. Following are the examples of process:

- a. Appointment scheduling is easy and flexible.
- b. The medical records system is well organized and coordinated among all providers.
- c. Referrals are timely and include coordination of care among providers and appropriate follow-up.
- d. Emergency care is available.
- e. Individuals with developmental disabilities receive annual physical assessments to screen for any new problems and follow up on ongoing medical concerns that would include:
 - screening and laboratory tests appropriate for age, as determined by standard practice for the general population: e.g., Pap smear, prostate exam and mammogram etc;
 - screening based on the individual's specific diagnosis, e.g., thyroid levels and cervical spine films for individuals with Down Syndrome;

- necessary laboratory tests and follow up based on chronic medical conditions, e.g., seizures, gastroesophageal disorders and chronic pulmonary problems, etc;
- providing preventive care as necessary, e.g., yearly flu shots to vulnerable individuals;
- medication and dosage reviews based on diagnosis;
- individuals, family and caregivers being made aware of warning symptoms of medication side effects.

C. OUTCOMES, as assessed by a standardized scale, refers to measuring the impact or results of health care intervention.³³ Outcomes can be assessed for individuals or groups. Healthy People 2010 has a comprehensive set of objectives to improve health of all people. The objectives of Healthy People 2010 are listed in the Appendix. It includes Health Promotion and Disease Prevention goals and can serve as a model for DDD to develop its goals and objectives to improve health of individuals with developmental disabilities. The following are some examples of outcomes:

- a. Standardized scales such as *Rand 36 Item Health Survey* and *The Quality of Well Being Scale*
- b. Consumer Assessment of Health Plans (CAHPS).
- c. Improvement of management of thyroid and cardiac functions in individuals with Down Syndrome.
- d. Improved management of pressure ulcers in non-ambulatory individuals.

D. SATISFACTION WITH SERVICES indicates positive feedback from the individual's perspective. The following are examples:

- a. The individual, family and/or caregiver are satisfied with the way care is provided by the health care provider and health care staff.
 - Clinic staff is sensitive to the needs of individuals and respectful.
 - Atmosphere is friendly toward the families and individuals.
 - The health care provider and office staff incorporate privacy and respect into interactions with individuals.
- b. The individual's physical health is improved.
 - There is improvement in acute symptoms, e.g., pain, nasal congestion, breathlessness, etc.
 - The activities of daily living are enhanced for the individual.
- c. The individual's mental and emotional health is improved
 - Social and psychological functions are improved, e.g., interest in social activities, feeling good about themselves, their role in society, etc.
- d. Communication with the health care provider is improved.
 - The health care provider has communicated about the diagnosis, follow up directions, an explanation about the prognosis, side effects of medications, etc.
 - The health care coordinator has coordinated the individual's care with other health providers.

VI. OTHER FINDINGS AND RECOMMENDATIONS

During the reviews, discussions, and analysis leading to these recommendations, the task force became aware of additional related issues having an impact on health care outcomes. The main issues are adequate reimbursement to health care providers, training on health care issues to individuals, families and caregivers, and health education, and prevention.

1. Health Promotion and Disease Prevention

The goal of the Healthy People 2010 report is stated to be “promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the U.S. population.”

Certain misconceptions exist about the health of individuals with disabilities that have contributed to the lack of health promotion strategies employed with individuals with disabilities. The task force recognizes the importance of health promotion and how it can positively affect health outcomes for individuals with disabilities. According to International Association for the Scientific Study of Intellectual Disabilities and Inclusion International, “People with disabilities should receive the same array of lifespan preventive health practices as those offered to the general population.” Some examples of wellness and prevention issues are: immunization, blood pressure, cholesterol and weight management along with preventive screening for various cancers and preventive screening for women. Additional healthy living practices include healthy nutrition, physical activity, stress management, and avoidance of risky behaviors such as tobacco use, substance abuse and unprotected or multiple sexual partner activity.

The members of this task force recommend that, as DDD implements the task force recommendations contained in this report, it take seriously the guidelines put forth in Healthy People 2010. The task force feels it is critical to understand that health promotion involves looking at the “whole person” which includes his or her medical, physical, emotional and societal needs as he or she lives in community.

2. Education about Medical issues for Individuals, Families and Caregivers

Many individuals with developmental disabilities require assistance from family members or residential staff to meet the activities of daily living. Families and caregivers play a large role in coordinating proper health care for individuals with developmental disabilities. According to the Special Olympics Committee on Health Care Report,¹ caregivers should be provided with education in order to help them understand how to recognize health problems and access appropriate health care.

It is important that families and staff providing care to individuals receive training and continuing education to improve their abilities to provide care and support to individuals with developmental disabilities. Some examples of education to caregivers include the most from medical appointments, how to supervise medication administration, identifying and preventing aspirations, recognition of symptoms of health conditions as well as the ability to recognize specific danger signals for an individual’s specific medical condition, and dealing with medication refusals and other medical issues related to an individual.

People with disabilities should receive the same array of lifespan preventive health practices as those offered to the general population.

... provision of culturally competent and culturally appropriate services has the potential to improve patient outcomes and the efficiency and cost-effectiveness of health care delivery

3. Cultural Competence

Individuals with developmental disabilities from different locations, race and ethnicity have different needs; therefore, it is important that services are delivered with cultural sensitivity and competence. Diversity in the workforce to represent the population being served is needed to provide quality service. Cultural and linguistic competence implies an ability by health care providers and organizations to understand and respond effectively to the cultural and linguistic needs brought by individuals with developmental disabilities to the health care setting. A culturally and linguistically appropriate response would include interpreter staff; translated written materials; sensitive discussions about treatment consent and advance directive forms; clinical and support staff who know to ask about and negotiate cultural issues; appropriate food choices; and other measures. The provision of culturally competent and culturally appropriate services has the potential to improve patient outcomes and the efficiency and cost-effectiveness of health care delivery.

4. Increasing Access to Health Care Coverage

This task force learned that, according to best estimates, approximately 9% of the individuals currently enrolled as clients of the Division of Developmental Disabilities have no health insurance coverage. This is of great concern to members of this task force because of the special health care issues of individuals with developmental disabilities.

For individuals who do not have public or privately funded health insurance coverage, health care can be provided through existing safety net models such as Community Clinics or Residential Habilitation Centers (RHCs). As these individuals are identified, they can be assisted to obtain eligibility for public funded health insurance and to locate a community health care provider.

5. Adequate Reimbursement to Health Care Providers

Most individuals with developmental disabilities in Washington State are covered under Medicaid Fee-for-Service. Reimbursement for care of individuals with developmental disabilities does not reflect the increased time and energy required by the health care providers to adequately and sensitively care for these individuals.³² The task force members expressed concern that health care providers would not continue seeing individuals with developmental disabilities unless compensated adequately. According to Crocker ²² many individuals with developmental disabilities require care and coordination of services that do not fit the traditional care pattern. Health care providers are reimbursed through Medicaid far below prevailing customary fees. He further stated that physicians and nurses couldn't recoup the unusual amount of time spent in evaluating health problems or communicating those findings to responsible agencies and other interested parties. Another limitation of the reimbursement system is that it covers only direct care services; many individuals can benefit from indirect services such as prevention, coordination, education, and training.

According to the Special Olympics Report, ¹ the present reimbursement system must be modified to encourage providers to treat individuals with developmental disabilities, and adequately reimburse those who choose to work with this population.

This group would like to recommend that the current payment system be re-examined to take the above issues into consideration.

VII. CONCLUSION

The task force has identified areas of concern about the health care delivery system for individuals with developmental disabilities. The task force recommends that the Division of Developmental Disabilities provide the leadership necessary to promote comprehensive, culturally competent, individualized, community-based health care including prevention and wellness. At the heart of these changes must be the individuals and their families.

In order to recommend health records options and ways to support health care providers, we saw the need for systems changes at the individual and population based levels. The members recognize the need to monitor the effectiveness of system changes once they have been implemented and so examined assessment techniques to measure the effectiveness of changes.

While the task force recognizes that there are costs associated with some of these recommendations, it recognizes the significant cost of not providing these services to individuals with developmental disabilities. Efforts should be made to enhance knowledge and skills, empower people to become healthier, and encourage improved access to health care providers. The task force recommends that the Division of Developmental Disabilities use this document as the framework to implement these changes. A group of consumers and providers could be convened to develop an implementation plan.

The task force recommends that the Division of Developmental Disabilities provide the leadership necessary to promote comprehensive, culturally competent, individualized, community-based health care including prevention and wellness.

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APPENDIX I

Examples of Standardized Health Records

1. Personal Health Journal

Health Education Awareness Resource Tool (H.E.A.R.T Tool)

- Consumers (individuals with developmental disabilities) keep this journal with them wherever they go.
- Consumer takes journal to all medical and dental appointments and asks the health care providers to update the information.
- Consumer updates personal information.
- Routine appointments are scheduled according to wellness exam schedule.
- The following are the main sections:
 - ✓ Personal information section has name, living situation, emergency contacts, case manager's name, primary physician and dentist's name, insurance information, special medical conditions, and regularly taken medications.
 - ✓ "About Me" section has details of behavior and ongoing medical conditions, how medications are taken, adaptive equipments used and physical limitations as well as communication needs.
 - ✓ "More about Me" has additional information on living situation, vocational details, special abilities, activities and hobbies.
 - ✓ Education record.
 - ✓ Testicular or breast self-exam record/ chart.
 - ✓ Menstrual record chart.
 - ✓ Doctors visit, specific problems, duration of symptoms and treatment.
 - ✓ Doctor's visit contains doctor's response, medications, follow up and what should be expected and what to do if expected does not happen.
 - ✓ Wellness Chart is a grid to record: blood pressure, vision, hearing, Pap test, mammogram, prostate, fecal occult blood, and total cholesterol as well as immunizations.
 - ❖ Communication help.
 - ❖ Past illnesses.
 - ❖ Mental health record.
 - ❖ Dental record.
 - ❖ Medication Record.
 - ❖ Doctor visit and hospitalization log.
 - ❖ Family medical history.

2. MCare '*Taking Charge of my Health Tool Kit*'

It has tools for individuals with disabilities who want more say in their health care services. (MCare is the national clearinghouse on long-term supports and services for individuals with disabilities and their families at the Institute of Disability, University of New Hampshire). The Tool Kit has the following items:

- "*Listening to Me and Building on My Strengths*": This is a six-part brochure for health care professionals from the perspective of an individual with disabilities. It attempts to convey the information from the perspective of someone who has a

disability. “*Listening to Me and Building on My Strengths*” also reinforces how each person has their own definition of good health and how they would like to make health care choices.

- “*A Tool to Assist Individuals with Disabilities in Planning Positive Outcomes from their Health Care Services*”: This tool was designed to help individuals with disabilities and their families, friends, and advocates in thinking through their health care needs and goals.
- “*A Tool to Assist Individuals with Disabilities in Communicating with their Health Care Provider*”: This tool helps individuals prepare a written document to share with their health care provider. The tool was designed to help bridge the communication gap between the provider and person with disability by advising health care providers what accommodations can work best for the individual, and reinforcing the concept that the individual with the disability is the expert of his/her life.
- “*Quick Check*”: This form informs an individual with a disability and/or his/her family, residential provider and friends when his/her next health care visit is scheduled and what they need to remember to bring to their appointment.

3. Standardized Medical Chart: “Community Accessibility Project” by Dave Shurtleff 1992.

I. Main Chart Information

Complete Medical, Dental and Behavioral Histories, plus

II. Succinct Summaries of Health Care Information

At Time of Appointment

Contact Form

1. Recent medical history: why we are here, last visit’s notes if pertinent.
2. Patient’s administrative information.
3. List of current meds, dosages, intervals, and allergies and drug interactions.

Face/Cover Form

1. Chronology of health care (standing physician orders).
2. Emergency contacts (parents, staff, guardian, and employer) in case of immediate hospitalization.
3. Medications summary (particularly with psychotropics and anti-convulsants), which highlight contraindicating medications.

Informed Consent Forms

1. Patient/parent/guardian authorization for care.
2. Emergency release of information consent.

At Post Appointment

Follow-up. Written instructions to other caregivers prepared by the attending caregiver and reiterated to the physician at the time of appointment.

III. For People Considered Medically Fragile

1. List of other health care providers and phone numbers.
2. Crisis indicators.
3. More detailed information provided in *Contact Form*.

IV. For People Participating in Independency Programs

Self-Medication Program Information:

1. Schedules and methods of implementation.
2. Photocopies of prescriptions.
3. History of program success (evaluation).

CLIENT HEALTH SUMMARY

1. Name _____ 2. Birthdate _____ 3. SS# _____

4. Person to contact in emergencies: _____

5. Individual's Legal Guardian: _____ Self _____ Other (Please specify) _____

Medicaid # _____ Medicare # _____ Other Ins. _____

6. Last Complete Physical:

Date _____ By _____

7. Last Complete Dental Exam:

Date _____ By _____

8. Personal Physician: _____

Name

Address

Telephone

9. Personal Dentist: _____

Name

Address

Telephone

10. Other health specialists who have worked with the individual during the past two years (doctor, nurse practitioner, dentist, mental health specialist, etc.)

Name/Specialty	Address	Telephone

Please star (*) the one person listed in item 8, 9, or 10 who knows the individual best.

11. Individual's reactions to medical/dental care: _____

12. Known allergies to drugs: _____

Other allergies (food, inhalants, insect bites, etc.) _____

Recommend precautions: _____

13. Current Medications (include non-prescription items, i.e., vitamins, etc.)

Medication	Dose	Date Started	Comments/Side Effects	Reason for Use

INTERNAL FOLLOW-UP MEMO

The following illustration depicts a generic form available at most office supply stores. The form provides for an original and a duplicate copy. Physician's orders are recorded on the form at the time of the appointment. The original copy is forwarded to the unit supervisor and the duplicate copy is retained in the client's comprehensive record.

MEMORANDUM

FROM: (Physician)
(Physician Orders)

Telephone:

Recorded By: _____

COPY 1 TO STAFF

COPY 2 TO RECORDS

SUPPLEMENTAL CONTACT FORM

Medically Fragile*

Patient's Name _____ Date: _____

Report prepared by: _____ Phone: _____

SIGNIFICANT PAST MEDICAL HISTORY:

DIAGNOSIS

OTHER HEALTH CARE PROVIDERS

Name	Specialty	Phone
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HEALTH CARE FLOW SHEET: CHRONOLOGY (Use reverse side if necessary)

Date	Provider	Treatment
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Signature of Preparer: _____ Date: _____

**Provide in addition to initial Contact Form*

Appendix 2

A. EXAMPLES OF WEB BASED ELECTRONIC RECORD SYSTEM

1. 4HealthyLife.com: The mission is to bring the doctor's office into the patient's computer with secure Internet medical history storage and patient empowerment services. Patient enters information about their medical history by doing Self Health Assessment. There are step-by-step guidelines to input information in various health categories.

The patients can update their records at any time, view them, and edit the records. It would allow one to print a wallet card and the patient is instructed to staple this card to their insurance card. Access to the record is by password. Users can give the access code to their doctor to access information. Charge is \$24.99 per year.

2. PersonalMD.com: The only medical web site that features medical record management and E-File which enables members to store and retrieve personal medical information including paper based records such as EKGs, X-Rays, and lab results. A Personal MD-ER card is issued to help in emergency situations. The physicians, if authorized, can access member patients' medical records. PersonalMD offers following:

- Personal Medical Record – incorporates paper-based documents.
- Emergency Card - Contains instructions to retrieve complete medical information via Fax or internet;
- E-File - Stores and retrieves documents including living will.
- Medication Reminders - Receive reminders via pager, cell phone or other wireless device.
- Interactive Health Calendars- schedule appointments and view reminders;
- Personal Health and Medical Content Homepage and Newsletter.
- Drug database, Drug interactions, Health Encyclopedia and Medical Dictionary. The cost is \$29.95 per year

3. Care Simply: Care Simply allows up to 25 members of a care team to access a secure online care file 24 hours a day. Care notes can be shared with different members of an interdisciplinary team. The scheduler is allowed to make appointments and coordinate efforts of all team members. The site claims security features to include encryption of all pages and personal information. The servers are kept in a physically secure, environmentally protected facility. It costs \$9.95 per month.

B. THE FOLLOWING BROAD CATEGORIES ARE INCLUDED IN A PERSONAL HEALTH RECORD³⁰

1. Personal information
2. Family medical history
3. Immunization history
4. Allergies to food and drugs
5. History of personal illness or past procedure
6. Medications or other supplements
7. Contact information for other health care professionals/clinics
8. Other components:
 - Vital signs recording
 - Graphing and trending of health care data
 - Visit information
 - Lab and radiology results
 - Medical record security audit
 - Mental Illness history
 - Discharge summaries
 - Daily living habits (smoking, diet exercise, etc)
 - Drug interaction checks
 - Health goal planning
9. Additional features
 - A wide variety of reputable educational resources
 - Scheduling functions and appointment requests
 - E-mail notification of appointments
 - Data exchange with health care practitioners
 - Advanced directives and living will functions
 - On line communities and chat rooms
 - Listing of other health care providers in local areas
 - Event listings
 - Product shopping
 - Link to other health care services
 - Emergency card or Member ID card
 - Information resources such Medical Test Handbook to provide listing and description of different medical tests and their interpretation
 - Ability to maintain a family member's health record
 - Live data exchange with health care provider

Appendix 3

International Classification of Impairments, Activities and Participation (ICIDH)

The World Health Organization (WHO) has a mandate to develop a common global language in the field of health, *International Classification of Impairments, Disabilities and Handicaps*. The new version has “Activity” instead of “Disability” and “Participation” rather than “Handicap”. It also provides a framework for understanding the dimensions of disability and functioning at three different levels: body, person, and society. Some examples of how ICIDH –2 can be useful:

- Individual level evaluation.
- Assessment of individuals, e.g., what is the health condition and level of functioning?
- Individual treatment planning, e.g., what interventions would maximize functioning?
- Self-evaluation by consumers.
- Social or organization level evaluation.
- How many people use the services?
- How they get the services?
- Needs assessment at various levels of disability.
- Four dimensions - Functioning, Characteristics, Positive, and Negative aspects.

Appendix 4

HEALTHY PEOPLE 2010

A. Goals

Healthy People 2010 has two goals:

1. Increase quality and years of healthy life, and
2. Eliminate health disparities

B. Leading Indicators

The Leading Health Indicators will be used to measure the health of the Nation over the next 10 years. Each of the 10 Leading Health Indicators has one or more objectives from Healthy People 2010 associated with it. As a group, the Leading Health Indicators reflect the major health concerns in the United States at the beginning of the 21st century. The Leading Health Indicators were selected on the basis of their ability to motivate action, the availability of data to measure progress, and their importance as public health issues.

Following are the Leading Indicators:

- a. Physical activity
- b. Overweight and Obesity
- c. Tobacco use
- d. Substance abuse
- e. Responsible sexual behavior
- f. Mental Health
- g. Injury and violence
- h. Environmental quality
- i. Immunization
- j. Access to health care

C. Objectives for individuals with Disabilities

The Healthy People 2010 Report has the following objectives for the health of individuals with disabilities:

1. Include in the core of all relevant Health People 2010 surveillance instruments a standardized set of questions that identify “people with disabilities”
2. Reduce the proportion of children and adolescents with disabilities who are reported to be sad, unhappy, or depressed
3. Reduce the proportion of adults with disabilities who report feelings such as sadness, unhappiness, or depression that prevent them from being active.
4. Increase the proportion of adults with disabilities who participate in social activities.

5. Increase the proportion of adults with disabilities reporting sufficient emotional support.
6. Increase the proportion of adults with disabilities reporting satisfaction with life.
7. Reduce the number of people with disabilities in congregate care facilities, consistent with permanency planning principles.
8. Eliminate disparities in employment rates between working-aged adults with and without disabilities.
9. Increase the proportion of children and youth with disabilities who spend at least 80% of their time in regular education programs.
10. (Developmental) Increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities.
11. (Developmental) Reduce the proportion of people with disabilities not having the assistive devices and technology needed.
12. (Developmental) Reduce the proportion of people with disabilities reporting environmental barriers to participation in home, school, work, or community activities.
13. Increase the number of Tribes, States, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers.

Appendix 5

Medical Care Task Force Implementation Categories

A. DDD can accomplish on its own with current or additional resources

- ☐ Health Coordinators/Person Centered Health Planning
- ☐ Provide a toll free number for assisting health care providers with specific medical issues related to developmental disabilities. (*Might hook up with MEDCON – a toll free consultation and referral; service of the UW School of Medicine and it's primary teaching hospitals*)
- ☐ Maintain a web site with resources for health care providers, individuals, and families
- ☐ Serve as a resource to health care providers, residential providers, and families (Centralized Statewide Support)
- ☐ Educate and train individuals with developmental disabilities, families, and care givers about wellness and prevention
- ☐ Referral assistance for care of individuals' medical needs (within a Regional Medical Resource Center)
- ☐ Coordination of specialty referral. For example, Orthopedics, Neurology, Podiatry, Gynecology, Physical Medicine, and Psychiatry, etc.
- ☐ Outreach, onsite consultation and training to the residential care providers and community based services such as work sites or schools
- ☐ Assisting medical practitioners needing help by linking them to those clinics with expertise in DD health issues
- ☐ Utilization of Residential Habilitation Center Staff expertise
- ☐ Health care treatment of individuals with developmental disabilities who cannot find or afford a community health provider and assist in connecting them with a community provider.
- ☐ Identify resources in the community
- ☐ Support Staff and other professionals' training
- ☐ Identify the need for and provide the training of DDD Resource Case managers, Residential Providers, and Families
- ☐ Select items from each of these domains to measure the effectiveness of health care provided to the individuals with developmental disabilities but select only those outcomes that are commensurate with the efforts and implementation. (*Including Culture Competence*)

B. Needs to be accomplished by DDD and other relevant DSHS agencies

- ☐ Medical Home for Everyone
- ☐ A Standardized Medical Form
- ☐ An identification card with a summary of medical information
- ☐ Health Passport System
- ☐ Web based Medical Records
- ☐ Increasing Access to Health Care Coverage
- ☐ Adequate Reimbursement to Health Care Providers
- ☐ A system to ensure that medical records and necessary data are accessible to all providers involved in the care and coordination of medical issues

C. Needs to be accomplished by DDD and DSHS External Partners

- ☐ Develop and coordinate curriculums for medical, nursing, and other allied health schools (*coordination with Universities and colleges*)
- ☐ Educate and train individuals with developmental disabilities, families, and care givers about wellness and prevention. (*Collaborate with communities agencies such as the ARC*)
- ☐ Training programs for primary care providers, community nurses, clinics, hospitals, and emergency medical response teams. (*Coordinate with Universities, ARC, etc.*)
- ☐ Coordination with the University of Washington and community hospitals for residency training programs in Internal Medicine, Pediatrics, Family Medicine, Neurology, and Psychiatry
- ☐ Coordination with Medical and Nursing Schools and other allied health schools to provide opportunities for practicum training
- ☐ Based on the needs of a particular region, especially in rural areas, out reach by traveling teams specializing in providing care. The traveling teams could assist primary care providers by consulting and by providing training. Some regions might use “tele-health” using Internet technology to utilize the expertise of University of Washington or other experts outside of Washington State
- ☐ Training to individuals with developmental disabilities who cannot find or afford a community health provider and assist in connecting them with a community provider (*Coordinate with Universities, ARC, etc.*)
- ☐ Education and training to individuals with developmental disabilities, their families, and caregivers on health related issues
- ☐ Formal education opportunities for students in medical, nursing, and allied health profession schools
- ☐ Formal education opportunities for Resident Physicians
- ☐ Continuing Medical Educational Opportunities for Practicing Physicians, Nurse Practitioners, and Physician Assistants
- ☐ Mini-fellowships for health care providers
- ☐ Support clinics serving individuals with developmental disabilities
- ☐ A system to ensure that medical records and necessary data are accessible to all providers involved in the care and coordination of medical issues
- ☐ Supporting local clinics that provide services to individuals with developmental disabilities

D. Requires legislation/federal intervention

None

Other:

- ☐ A system to ensure that medical records and necessary data are accessible to all providers involved in the care and coordination of medical issues. (*Requires DDD to figure out legal issues involved in this system with the DSHS attorney*)